National Database for the Procurement and Transplantation of Kidneys

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I. Introduction

In the fall of 1986, the United Network for Organ Sharing (UNOS) was awarded a contract by the federal government to create a National Organ Procurement and Transplant Network. Among the tasks specified in the contract was the creation and maintenance of a national database of recipients waiting for organs. To a large degree, a nationwide database system used in the procurement and transplantation of kidneys has been in existence for over ten years. This system has shown phenomenal growth over the past four years and is providing a much needed service to end-stage renal disease patients across the nation.

This paper presents an overview of the database and hardware that now exists and is used by over 200 procurement and transplant hospitals in the United States. The database contains information which is accessed by several sophisticated computer programs to match a donor organ with the recipients who offer the highest probability of a successful transplant. New fields are often added to the records in the database in order to take advantage of the most recent scientific discoveries relating to kidney transplantation. As a result, the database which exists today contains much more extensive information than the system which existed only five years ago.

II. Hardware

When the UNOS database system was originally implemented, the General Electric Mark III timesharing service was utilized. This system provided reliable service and the programming capabilities needed by the initial database system. However, as the size and sophistication of the database system grew, the costs and limitations of the timesharing system became prohibitive. The cost and availability of large mini-computer hardware plus the growing need to have more control of the operations and implementation of the database system made it advantageous to purchase a dedicated computer. In 1981, an IBM Series I was purchased and the database system was rewritten. Rapid growth and more emphasis placed on the interactive use of the facility with a wide range of different terminals led to the purchase of the current hardware configuration.

The current database resides on a DEC VAX-8530. The computer system contains 16 megabytes of memory, 912 megabytes of disk storage, and a 6250 BPI tape drive. Dial-up access is made either through one of five national WATS lines at speeds up to 2400 baud, or through a public access network system, Telenet. For emergency power, the VAX system has battery backup which will provide 90 minutes of service at full power requirement. A DEC VAX 11/750 serves as a backup for the 8530. The 11/750 is networked to the 8530 utilizing DECNET and changes to the database on the 8530 are transmitted to the 750 every thirty minutes. Thus, the database on the 750 is identical to the database on the 8530 except for the thirty minute delay. When a hardware failure (such as a system crash) is sensed, all of the external communication lines are automatically switched to the backup system through the use of an Infotron intelligent switch. The backup system is also used for software development and other internal computer needs to minimize the conflict with the transplant-oriented mission of the primary system.

III. Database Description

The record format of the current database is shown in Table 1. All data is stored as ASCII characters in a file keyed on three variables. The primary key is the blood group, the secondary key is the transplant center code, and the

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tertiary key is the recipient name. Dates of the recipient's initial registry and record modification are automatically generated by the user interface software.

The demographic information for each recipient is shown in Table 1. The medical data includes blood type, human leucocyte antigens found in the recipient tissue, haplotype code, current and peak PRA values, and unacceptable antigens. Antigen matching is a main criterion used in the matching of donors and recipients. An antigen is a substance that triggers an immune response. If the antigens found in the donor tissue do not match the antigens found in the recipient's tissue, the recipient's immune system may try to reject the transplanted tissue. Unacceptable antigens are defined when there exist individual antigens to which the recipient has pre-existing antibodies. The haplotype code is an indicator (yes or no) which tells whether or not the laboratory has tissue typed relations (mother, father, siblings, children) of the recipient. The purpose of haplotypes is to identify which A and B antigens reside on the same gene.

TABLE 1

Data Record for Renal Recipient Database File

Variable	Length	Description
ABO	2	Blood type A, B, AB, O
OCENTER	4	Owner center of recipient
RNAME	12	Recipient name
HOSP	4	Hospital where recipient is located
AGE	2	Age of recipient in years
SEX	1	Recipient sex M/F
RACE	1	Recipient race: B or N: Black/Negro W or C: White/Caucasian I : American Indian O,M,A : Oriental, Mongoloid, Asiatic L : Latin
RA1	2	First A antigen
RA2	2	Second A antigen
RB1	2	First B antigen
RB2	2	Second B antigen
RDR1	2	First DR antigen
RDR2	2	Second DR antigen
BLANKS	10	Free space
LEWIS	1	Lewis antigen P/N
HAPL	1	Haplotype code Y/N
PPRA	2	Peak PRA value
CPRA	2	Current PRA value
RTX	1	Number of transplant
UN	1	Boolean for unacceptable antigens Y/N
UHL1 - UHL12	2 each	Twelve A/B unacceptable antigens
UDR1 - UDR4	2 each	Four DR unacceptable antigens
UBW	1	Unacceptable BW antigens
RACPT	1	Min number of matched antigens required
RSTAT	1	Recipient status code: 0 Medical emergency, critical 1 Active 2 Recipient temporarily inactive 3 Hospital temporarily inactive 4 thru 7 Foreign national codes
EDATE	7	Entry date of recipient
MDATE	7	Date of last modification
DUMMY	19	Free space

Procurement and transplantation hospitals or agencies access the database directly through a user interface program. This program provides the following capabilities:

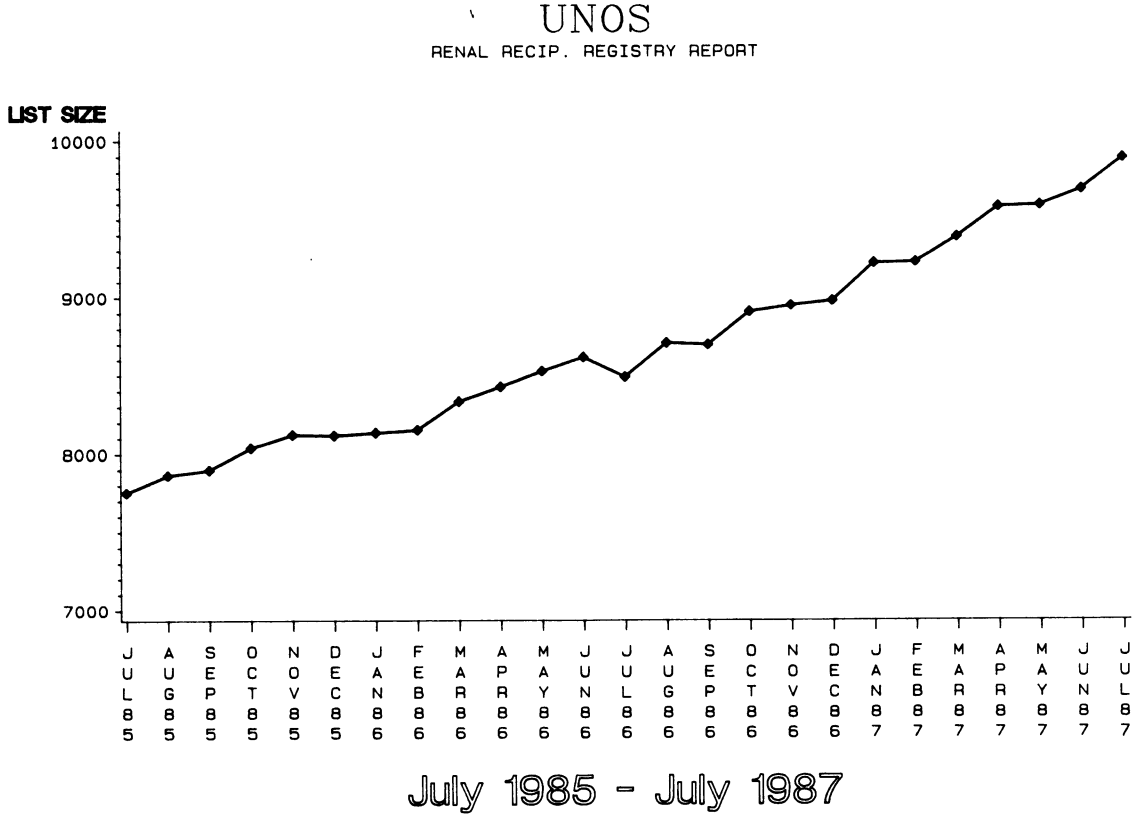
1. Add a recipient record to the database
2. Delete a recipient from the database
3. Modify a recipient currently on the database
4. Modify the current Panel Reactive Antibody (PRA) value of a recipient
5. Change the status of a center
6. Print routine

When a recipient is added or modified, all fields are checked for proper data. Users may only add and modify recipients that are associated with their center. High PRA values indicate an increased level of pre-formed antibody, or sensitization, and could result in rapid organ rejection. Because these values often change through transfusion or other exposure to foreign antigens, a special routine was developed to allow rapid update of the PRA. The status of a center may be changed to enable or disable all recipients associated with a center. The print routine allows the user to obtain a listing of all recipients associated with their program.

IV. Use of the database

There are currently over 9,500 renal recipients (see Figure 1) waiting with entries in the database. This compares with 7,000 recipients in January, 1985. This shows a growth of about 92 recipients per month. Usage figures over the same period of time show that about 550 to 600 new recipients are added to the database each month. Between 250 and 300 recipients are typically removed each month because they receive a transplant. Another 150 to 200 recipients are usually removed for various other reasons such as death, moved away from the center area, or changed their mind about the transplant.

Figure 1



Along with the increased number of recipients on the renal waiting list, the recent increase in the registration of non-renal recipients, such as heart, heart/lung, liver, pancreas and cornea have resulted in a major increase in the use of the UNOS computer system. The total number of recipients waiting for a transplant on the system is over 10,500. It is anticipated that this will continue to increase. CPU hours consumed in the transplant-oriented programs grew from 202 hours in June, 1985 to over 530 hours in January, 1987. Various system performance enhancements, along with planned excess capacity, have resulted in minimal system degradation by this growth.

V. Future concerns

The past sustained accelerated growth of the database is expected to continue because of the recognition by the federal government that this is the United States national transplant database. This will result in a continual need for upgrading the hardware. In order to facilitate the exchange of data between UNOS and various international organ registries, compatible record formats and communications protocols will be developed. Other future plans include the development of post-transplant databases for other tissues and organs such as livers, hearts, lungs, heart/lungs, pancreas and corneas. Future hardware plans include the development of voice activated communications which will allow centers to access the database without the use of a terminal or modem.

Bibliography

1. United Network for Organ Sharing, Computer User's Manual, 1985.

2. Pierce, G.A. "The Establishment of a Kidney Bank, "American Association of Tissue Banks, 1977.

3. Spees, E.K., Mendez-Picon, G., Vaughn, W.K., Reitz, B. "Cadaver Organ Procurement and sharing by SEOPF," Transplantation Proceedings, Vol. 16, pp. 177-179, 1984.

4. Spees, E.K., Vaughn, W.K., Peters, T.G., Reitz, B.A., Mendez-Picon, G., Goldman, M.H., Sanfillippo, F.P. "Procurement and Sharing of Cadaver Organs for Transplantation by Institutions of SEOPF," Dialysis, Transplantation, and Burn Journal, Vol. 1, No. 2, pp. 48-56, September, 1983.

5. Stulting, R.D., Ward, F.E. "A Computerized System for the Selection of Organ Transplant Recipients," Transplantation, Vol. 19, No. 1, 1975.